

Personal assistance

for independent living

Introduction

<i>Introduction</i>	<i>4</i>
<i>Adolf Ratzka - Towards An Operational Definition</i>	<i>5</i>
<i>Adolf Ratzka - What Is Personal Assistance?</i>	<i>7</i>
● <i>What Are The Alternatives To “Personal Assistance”?</i>	
● <i>In What Forms Has Assistance Been Available So Far?</i>	
● <i>False Independence</i>	
<i>HCIL (Hampshire Center For Independent Living) –</i>	<i>10</i>
<i>Developing Assistants Management Skills</i>	
<i>Adolf Ratzka - Brief Description Of The Swedish Personal</i>	
<i>Assistance Act Of 1994 (Lass)</i>	<i>12</i>
<i>Pitfalls Of Professionalizing Personal Assistance</i>	<i>17</i>
<i>Personal assistance in the light of employment</i>	<i>21</i>
<i>Occupation Profile:Personal Assistant</i>	<i>26</i>
● <i>Differences Between The Profile Of A Social</i>	
<i>Assistant And The Profile Of A Personal Assistant</i>	

Introduction

This bulletin arose from a practical need for implementation of the “Independent Living of the Disabled” programme and from the need of propagating and enforcing the idea of independent living. We observe that the public is still poorly apprised of the programme, there is still a lot of misunderstanding and ignorance among the experts, policy-makers, and last but not least, the disabled themselves, especially when we focus on the right for personal assistance. Many still do not understand it.

We are hoping that with these short and basic articles, we will contribute to greater awareness of the problem. Indirectly, we are also trying to awake as much of the disabled individuals as possible and stimulate their passion for assuming a more active role in various areas of social life.

As European citizens, we want laws in our country and region, which are equal or even better than those of the other countries. We wish to be heard on this subject, because we believe that such a thing is entirely possible and feasible. We know how to do it, we have the knowledge and we possess the needed will!

This bulletin is a collection of various texts, which describe different points of view with respect to personal assistance. Our intention was not the one of breaking them apart and creating an artificial linearity, because in doing so, we would extinguish their charge and destroy their unity.

Adolf Ratzka

Personal Assistance

Towards an operational definition

Persons with extensive disabilities need assistance by other people in their everyday lives with such activities as getting bathed and dressed or going to the toilet; with shopping, preparing meals, cleaning or doing the laundry; with such responsibilities within the family as doing the practical tasks involved in raising small children or assisting one's aging parents. Assistants help the user at work, about town and on travel. They assist in communicating or in structuring the day, as the case might be. In brief, assistants help with those activities which the user would have done by himself or herself, had it not been for a physical, sensory, mental or intellectual disability.

People who are dependent on others for the most basic needs of life face prejudices. For instance, somebody who is physically dependent on other persons may also be considered emotionally and intellectually dependent. Somebody who cannot pull up his or her pants like a small child, may be treated as a small child in other respects as well. The result is often over-protection and custodial care where other people make the decisions.

It is no surprise then that the Independent Living philosophy is most easily grasped by people who are dependent on assistance in their every-day lives. This is also the reason why the Independent Living Movement emphasizes the importance of the quality of assistance for users who want to achieve maximum independence.

"Personal" assistance means that users exercise the maximum control over how services are organised and custom-design their services according to their individual needs, capabilities, life circumstances and aspirations. In

particular, personal assistance requires that the individual user decides:

- who is to work,
- with which tasks,
- at which times,
- where and how

Thus, the individual user must be able to recruit, train, schedule, supervise, and, if necessary, fire his or her own assistants. Simply put, “personal assistance”, means that the user is the boss.

It is recognized that users with learning or mental disabilities will need support from third persons with these functions.

Personal assistance enables users to take their rightful place in family, at work and society with all the rights and duties that the general population takes for granted. With personal assistance persons with extensive disabilities need no longer be a burden on their families. Parents, husbands or wives do not need to stay at home and sacrifice their careers. Personal assistance users not only manage on their own, they can also take their share of household and child-rearing. With personal assistance we can attend school and educate ourselves, enter the labour market and become tax-payers. When we fall in love, our partners need not fear that they are about to sign up for a life-long 24 hour job.

April 1997

<http://www.independentliving.org>

Adolf Ratzka

What is personal assistance ?

„Personal“ connotes that the assistance has to be customized to my individual needs. „Personal“ also means that the user decides what activities are to be delegated, to whom and when and how the tasks are to be carried out. I think in a world of personal computers and personal telephones the term „personal assistance“ is quite descriptive.

What are the alternatives to „personal assistance“?

In English, the terms „attendants“, „personal care attendants“, „carer“, „home help“, etc are used. Most of these words contain the word „care“. To me this word carries the connotation of taking care of somebody who cannot take care of himself or herself. The relationship between „carer“ and „caree“ implied by this term is not one of voluntary association for mutual gain, it does not clearly state that the „caree“ is the one who decides what has to be done. The term „home helper“ indicates that „help“ is to support activities only in one's home as opposed to a lot of other places such as at work, on the bus, at a friends' house, on trips, etc. I am sure that in most languages we will find similar expressions which imply that we are helpless, somewhat stupid persons who, like small children, cannot look after themselves and need supervision. If we want to design services which get us closer to the goal of equal opportunities, we have to find expressions for such services which portray us as responsible and capable citizens who are in command of their lives and not as passive objects. Language both influences and reveals attitudes including our own attitudes towards ourselves.

In what forms has assistance been available so far?

Family as assistance provider

In most countries the most common form is the family. Reliance on the family may work for some time but the limitations - even under the best of circumstances - are given. Family members get older, they are risking their health in assisting us. Children often have to take too much responsibility too early in their lives. Adults cannot pursue their career and feel locked in. The results are relationships of mutual dependence, sacrifice and guilt. Where guilt is often mistaken for love.

Facing the alternative which in many countries is institutional placement of the disabled family member most families hold out as long as they can - often without any outside assistance - burdened by immense physical, financial and emotional strain.

Volunteers

In some places families get help from volunteers. The virtues of volunteerism are most often praised by conservative politicians whose motives are to cut taxes for the benefit of their voters. Obviously, users of assistance from volunteers cannot demand the same competent, punctual, and courteous work from volunteers as they might from assistants who are paid competitive wages. But in most instances users who utilize volunteers do not have that choice.

Stationary institutions

The alternative that most of us in Europe have is to live in some sort of institution. Institutions are administrative entities and as such are governed by the necessities of administering buildings, workers and inmates within the boundaries given by budget, labor unions, and state regulatory agencies. These constraints are expressed in a multitude of rules which cannot be adapted to the needs of each individual. Otherwise there would be chaos. As a result, a certain order has to be maintained to guarantee the smooth functioning of the whole. The individual's challenge, then, is to adapt himself or herself to the existing order both physically and psychologically without losing one's integrity as a human being. That is very difficult. One of the survival strategies is to develop a pleasing personality with which you can achieve privileges at the expense of other inmates who are not as adaptable.

The general results of institutional living are known as „hospitalism“, that is loss of social skills, foregone life opportunities, and stunted human growth. The problem we are facing in helping people who have been staying in institutions is that they often have lost their self-confidence and are frightened by the prospect of leaving their secure confinement.

A definition of an institution

Perhaps it is appropriate at this point to attempt a definition of an institution. I suggest that we face an institution if

- there is no other alternative,
- we cannot choose who is to assist us,
- the user has to adapt his needs to the needs of the whole scheme,
- there are written and unwritten rules regulating the assistance, rules over which the user has no control,
- the assistance is limited to certain hours, activities, locations (for example, you have to live in certain houses as opposed to living anywhere),
- the staff providing assistance is shared by several persons,
- there is a hierarchy with the user at the bottom of the pyramid.

If we accept this list of institutional characteristics, then most forms of assistance fall under this category.

False independence

Those of us who need assistance are used to restricted lives. For one, most of us have been exposed to the present rehabilitation philosophy which wants us to do as much for ourselves as we possibly can and even more. „Push your limits, try harder. Exercise, exercise. Don't get lazy, use your manual wheelchair, not your power chair!“

Our first goal, according to rehabilitation professionals, is to be independent and manage with a minimum of technical aids. Personal assistance should only be used as a very last resort, since it is considered a recognition of failure on the part of the professionals and ourselves. Or have any of us been taught by a rehabilitation specialist how to delegate tasks to other people? Many of us have accepted these professional priorities. Their purpose in life seems to get out of bed by themselves, get washed and dressed by themselves, to cook and clean. Never mind that it takes the whole morning. Never mind that they get so worn out that they have to rest the other half of the day to recover enough strength for going to bed. They may not have a job, they may not be able to do much outside the home, they may not have time and energy to get involved in disability politics and fight for equal rights. But they are proud of being independent.

The brainwashing that many of us receive in rehabilitation distracts us often effectively from painful comparisons with other people, our non-disabled friends, relatives and neighbors. How often do we allow ourselves to compare our lives with theirs? It can be painful to admit to oneself that we too would like to have a good job, a nice home and a family. But for many of us these things will be out of reach forever, if we do not have the possibility of delegating practical tasks to personal assistants. Ultimately, it is a question of self-respect. If we respect ourselves as persons of equal value, then we expect and demand the same lifestyle that others take for granted. Then, we will also want to use personal assistance as one of the tools to achieve these goals.

HCIL ((Hampshire Centre for Independent Living)

Developing assistants management skills

With little or no previous experience the disabled person seeking to live independently suddenly finds her/himself thrust into the role of employer. Not surprisingly the effective management skills essential to coping with the day-to-day matter of relating to her/his personal assistant are sometimes absent or under-developed.

The relationship between a disabled person and her/his personal assistants has a lot to do with simple human chemistry - but it isn't enough to leave it at that. Disabled people must adopt a responsible approach to the working relationship. It is not good enough to leave things to chance, or 'flying by the seat of one's pants'. The need for care and the control of care lie at the very heart of a disabled person's existence and we must do what we can to ensure success in our chosen lifestyle. This means that we need to be sensitive to the needs of personal assistants, both 'new' and long-standing personal assistants, and be constructive in the way we enable them to function.

Some common complaints among personal assistants are:

- The lack of a specific job description - leading to unequal expectations. Personal assistant understanding that you need one thing and you believing that you are to receive something else. (Adjectives such as 'less' and 'more' are often appropriate here.)
- The disabled person's inability to provide effective objective feed-back on performance. Personal assistants want and need something more than general 'complaints', 'bad temper', 'euphoric gratitude', or an (apparently)

‘indifferent silence’. Caring is a job and all humans require ongoing job satisfaction, which only the employer (the disabled person) can provide. Of course many disabled people have developed their own ways of dealing with these issues and it is not the purpose of this chapter to imply that the following is the only acceptable procedure. Rather it is to draw attention to a most important subject and to provide some ideas when considering it. Independent living advocates need to propose procedures that enable a disabled person to train and manage attendants more effectively. For this purpose we suggest the use of performance check lists.

<http://www.independentliving.org>

Adolf Ratzka

Brief Description of the Swedish Personal Assistance Act of 1994 (LASS)

The Legislative Basis is the Law LASS (*Lagen om Assisteringsersättning*) of 1994

The purpose is to enable persons with extensive disabilities to have a „good quality of life“, that is, to become more independent from their families, move out of institutions and become productive citizens. The law was inspired by the Swedish Independent Living Movement.

LASS gives the user the legally guaranteed right to receive funds for p.a.

The national Social Insurance (*Socialförsäkringen*) that is also responsible for health insurance, pensions, etc. The insurance is financed by state income taxes.

All persons up to the age of 65 who need a minimum of 20 hrs/week for such basic tasks as dressing, bathing, eating, communicating. A total of presently 7000 persons fulfill these criteria and are entitled to the payment. (Persons above the age of 65 or with need of fewer than 20 hrs/week can apply to their local government for a similar scheme. In that case the user has no legal right to receive cash payments. The local government may choose to provide the services in kind instead. Also, in that case another law applies (*socialtjänstlagen*) which obliges the local government to help in achieving a „reasonable quality of life“ only. Thus, fewer hours of assistance might be granted.

Assessment is conducted by trained staff at the Social Insurance. They are to consider a person's total life situation including such aspects as the user's responsibility within the household, at work, leisure time. Need is expressed in number of hours of assistance per week. Assessment also includes the length of the accounting period, i.e. the number of months after which the user has to pay back money for any unused hours. Within the accounting period the user can dispose of the hours, save or spend, as needed.

The maximum amount per hour is determined each year by the central government and is presently 20 ECU. This amount multiplied by the number of hrs/month that the user is entitled to is paid monthly.

Benefits from Social Insurance are not means-tested and do not constitute taxable income. Thus, the amount paid to assistance users does not depend on the user's or his/her family's income or wealth; only on the numbers of hours needed.

The monthly payment from Social Insurance can be paid directly to the user's bank account or, at the discretion of the user, to the user's service provider. After each month the user has to send to Social Insurance a signed statement specifying amount of money received and number of hours used for that month. After the end of the accounting period (see 2.1.5) user and service provider have to report any hours which were not used up. The amount of money equivalent to these hours will be subtracted from the next payment. Social Insurance can audit service providers.

The hourly rate is to cover the average costs of full wages including compensation for unsocial hours, employer's social fees, insurance, all employer's administration including advertising for assistants, assistants' costs when accompanying user, some assistive devices facilitating the assistants' work.

Service Delivery

Anybody. No requirements as to qualifications. Only limitations are age limits (stipulated by Swedish labor law) and the total numbers of hours worked during a month (stipulated by labor union contract).

Employment contracts with the unions in this field can be full-time/part-time monthly employment with same salary each month and severance payment at termination or on a per hour basis.

The Social Insurance money can be used to purchase services from a provider (local government, private company or user cooperative). In that case the provider is the employer for the assistants. It is also possible for an individual user to start up one's own company which, in turn, is the employer.

The service provider. Often users can express their wishes as to which assistants they prefer. In STIL's user cooperative model the individual user is solely responsible for recruiting. STIL has no common assistant pool since this would limit the individual user's discretion. The individual user can advertise anywhere and in any way, e.g. placing ads or by word of mouth.

In STIL's user cooperative model the individual user is responsible for training his/

her own assistants according to the user's individual needs. We do not believe in common training - except for training in ergonomics. Users either use experienced assistants to help in training new ones or, as recommended by STIL, trains each assistant himself/herself for full control over the training.

In STIL's user cooperative model the individual user is solely responsible to schedule, supervise, motivate and re-train assistants according to the user's individual needs.

STIL's user cooperative model allows the individual user full freedom over the recruitment and scheduling process. Thus, it is up to the user who will work, when and with which tasks.

Support for the Individual Personal Assistance User

The LASS law charges local governments with the task of informing persons who might be eligible for the payments. Also, disability organizations inform their members about the program and their rights. STIL conducts courses, distributes literature and has staff to answer questions during office hours.

According to Swedish law legal aid to low-income persons cannot be granted when persons appeal the Social Insurance's decisions (for example, the number of hours granted). Some disability organizations including STIL have staff on hand who will assist the individual to appeal decisions.

In STIL's user cooperative model membership in the cooperative and the scheme is awarded only to graduates of the „supervisor course“ which prepares the user for the task of becoming supervisor of his/her assistants. Course consists of 10 evenings covering such topics as How to use personal assistance to reach life goals; How to assess one's needs; How to apply and argue for the payment; How to recruit, train, supervise, motivate, terminate assistants; the necessary paperwork; the union contract, assistants' employment conditions, labor laws pertaining on to safety and health in the workplace.

STIL members have access to support from staff consisting of experienced personal assistance users. Also, peer support group sessions are conducted on the most frequent problem areas with assistants. We have also had a „buddy“ system where we have tried to link new and inexperienced members with members with long experience in running their own assistance.

In STIL's user cooperative model there are a number of members with intellectual disabilities. In most cases their legal representative - most often a relative - will take on the function of recruiting, training, and supervising assistants. In some cases where this support has not been strong or lacking STIL has tried to assist the respective member with a „deputy supervisor“ with the member's consent. The „deputy supervisor“, in turn, is supervised by STIL's office staff.

Evaluation

Social Insurance: after age 65 the user has to turn to local government which often entails lower quality of life. Also persons with needs of fewer than 20 hrs/

week would benefit from the scheme. Recently, changes have been ratified by Parliament which take away the right to personal assistance while in school or in day centers. Their staff of the institution is to assist. Clearly a big leap backwards.

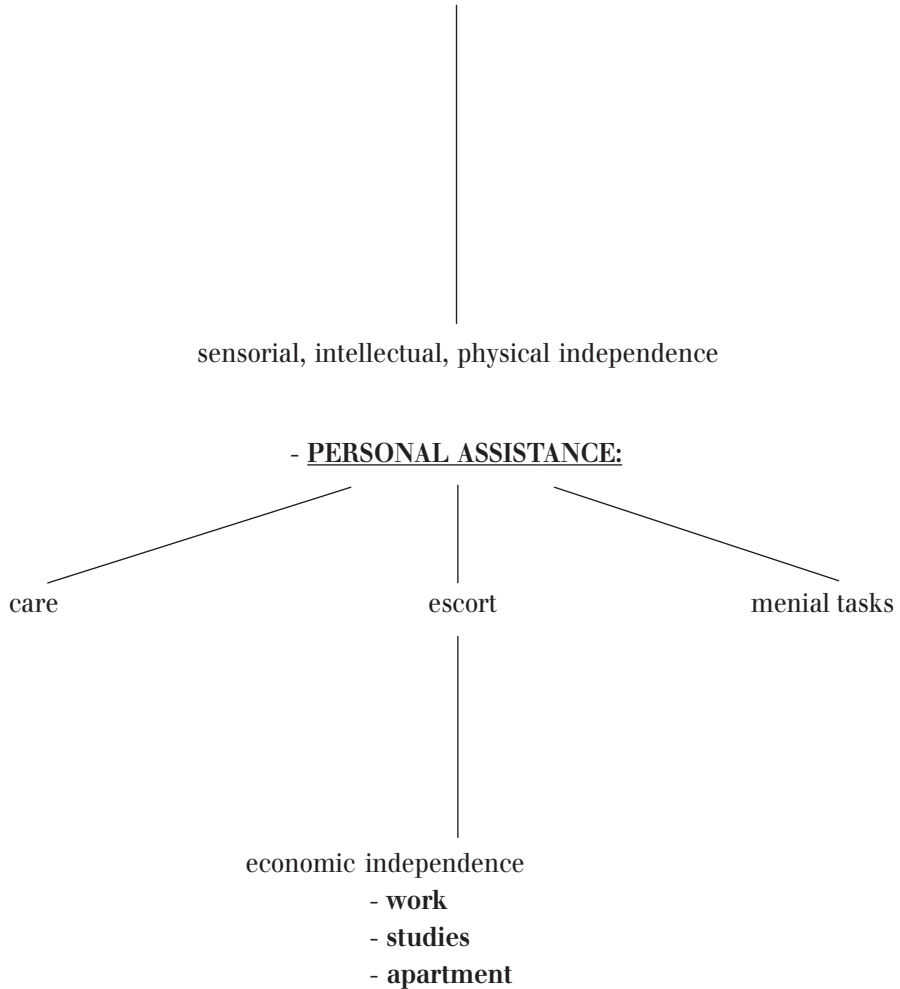
STIL's user cooperative model: Many features depend on the wisdom and enthusiasm of the leaders. According to the bylaws the board must be 100% assistance users. If not enough good people have the time and energy to serve, the scheme will deteriorate. Also, it is difficult to find personal assistance users for qualified staff positions. Availability of peer support depends on good and motivated members who will work in this field. Solutions delegate a great deal of responsibility to the individual member. Thus, the cooperative is quite vulnerable, if some members do not live up to their duties and, for example, treat assistants unfairly. In that case, the cooperative's reputation suffers and labor unions might take action against us.

Good „buddies“ and „deputy supervisors“ are very hard to find. STIL has presently 190 members. It seems that given our rapid growth the need for „buddies“, „deputy supervisors“ and peer support staff far outpaces the number of able and willing members who want to work with these issues. Also, once somebody has become a member we cannot really force them to seek help in managing their affairs, since STIL respects each member's right to run their own lives without interference from others - as long as they do not violate other member's rights.

As to the limitations imposed on us by the law and the Social Insurance we have been demonstrating and lobbying to try to improve/fend off cutbacks. As to the limitations of the STIL model, we are still not finished with the job of building it. Its quality will always depend on the members. There has to be a critical mass of members with skills, motivation and solidarity.

<http://www.independentliving.org>

INDEPENDENT LIVING OF DISABLED PEOPLE



<http://www.ljudmila.org/yhd>

<http://www.independentliving.org>

Elena Pečarič

Pitfalls of professionalization of personal assistance

Personal assistance is the key element or rather a condition for independent living of the disabled people. One could try to define it as a physical assistance with all the tasks and activities, which a person cannot implement by him/her self because of his/her handicap, but does need them to be done in order to lead an independent and autonomous life. People who need personal assistance may have various kinds of disability: physical, sensorial and intellectual. Personal assistance can be classified according to the type of labour, but the types are often intertwined, namely: personal care, assistance at the workplace or help with performing various daily activities, escort and help to a disabled parent taking care of his/her child.

The term *personal assistance* (slo. osebna asistenca) has lately won recognition and is spreading in Slovenia, too. As a professional figure, it is gaining ground in Slovenia, although it is often misused and reduced to disused principles of help, such as nurses in the institutions, home care services, people employed in the residence communities and so forth. This, of course, is by no means permissible, since personal assistance incorporates certain vocational properties found in no other form of assistance, which are from the user's point of view indispensable in leading an independent life.

»Personal« assistance means that the user has as much control over organizing and designing the service of assistance as possible. The services are designed according to the needs, capabilities, living circumstances, conditions and wishes of an individual.

Existing services of assistance therefore cannot be named personal assistance, because they require the user to adapt to the requirements of the service and

not vice versa. The services are often implemented in a way that are limiting and pose an obstruction for the user in making his/her own choices and decisions; determining the location (i.e. communities), extent of the service, form of execution, implementers of the service, and the possibility of control. With other services, the user often has to accept the existing rules and the staff available. A common feature of such services is that they are hierarchical and the user is usually right at the bottom and has to adhere to the rules and decisions made by the people at the top. That is why the stress on the “personal” assistance also means that the user him/herself decides, which of the activities will be performed by the assistant, who will implement them and when and how the required service will be provided.

PITFALLS OF PROFESSIONALIZATION OF PERSONAL ASSISTANCE

Standardization:

- **unified criteria at the expense of disregarding the differences,**
- **requirement of knowledge and skill irrespective of type and range of labour,**
- **disregarding the individual requirements of the user,**
- **standard social work is based on medicalization and psychologization of the users.**

Formalization:

- **reduced flexibility of potential candidates and limitations on the market of labourforce.**

Education:

- **who will design the content and the extent of education?**
- **who will educate?**
- **what is the role or, in other words, where is the user in this process?**

Dangers of education:

- **transfer of institutional practices and methods of work,**
- **insertion of medical approach and treatment.**

That is to say, there are pitfalls and dangers, which every standardization and formalization inevitably brings about. It is because of the reduced flexibility of the occupation that must adhere to various needs and wishes of an individual user as well as to the market of the “appropriate” workers. Finally, yet more importantly, the possibility of acclimatization and the ability to bear disused and stereotypical practices is increased. We must not forget to make a priority list of individual users’ needs that all formalizations automatically exclude in favour of generality, average

and majority. There is a great threat of medicalizing the occupation and of the emergence of a patronizing approach to the user. However, this is what the individuals who wish to live autonomously are acutely rejecting and try to run away from.

The experts or to be more precise, the social workers who have recently been confronted with organizing and managing the “home help” service, and were previously familiar only with institutional care still lack knowledge and understanding or are unable to accept the “independent living” philosophy and the paradigm in which a service called “personal assistance” is implemented. However, many unfortunately do not know this paradigm. That is why we need to stress that personal assistance bears no relation to institutional or domestic care services. The threat that we see and that is already forming in places is the act of copying the institutional and tutelary way of care and work practices into local environments and into the user’s home. By doing this, the power of decision is yet again taken away from the user and the user is treated as an object of care and help.

USER



EMPLOYER

decides about:

- **who will work for him/her**
- **what are the employee’s tasks,**
- **how will they be completed,**
- **when and where.**

duties of the user:

- **to find and select an appropriate assistant,**
- **to educate him or her,**
- **to keep a record of presence and of other important data, which stem from duties concerning employment,**
- **to solve conflicts and supervise – to be able to dismiss an assistant from employment.**

As the leader, organizer and at the same time the user of the “Independent Living of the Disabled” project I can assert that the individuals who are the most suitable to work as personal assistants usually do not bear any relation social and medical occupations and experience with working in institutions or care centres. People with such a background are usually more open towards new experiences and are able to satisfy the user’s needs better and with more ease, because they

have no previous “knowledge”. They are not burdened with the rules of the profession, user’s diagnosis and other methods of proceedings and rules of behaviour. We, the users, can instantly sense a person who “already knows everything”, who “would like to help”, who “would like to work with such people” or has many years of experience on this field. As a rule, these people feel they are superior, or even better, they give an impression of happiness, because they have more options and do not feel they are missing anything. In their belief, the user is, in comparison to them, a striking contrast and must be helped and his or her life must be given a meaning. Such an approach and behaviour is completely unsuitable, insulting, and demeaning for the user and therefore we do not choose such people to work as personal assistants.

Of course, we do not believe that some basic training and education is not required. Still, the user plays the most important role in educating his or her assistant, as the user is the one who chooses. This way, the highly individualized approach can be preserved, which is an integral element for assuring the quality of the service.

The user bears a great responsibility, as he/she must educate his/her assistant properly, if he/she wants an assistant who will suit his/her needs. Let us diminish the fore judgement that not anyone is suitable to be a personal assistant, by which a certain category of people is meant – mainly, the so-called risk groups such as older persons, ex drug abusers, the people who are searching for their first job, single mothers... Practice has shown however that of all others, and because of their social position and stigmatization, these people are more sensitive and susceptible to perform this type of work. They are responsible, and conscientious and do not behave as “the normal in relation to the different”. Nevertheless, the user is of course always the one who makes the choice. Because we are different from each other, the possibility of choice must also be diverse and not fixed or formalized.

Now we come to find that the user is not automatically and a-priori able to manage his/her own personal assistance, that is, to be a good, conscientious, and above all responsible employer. The most challenging problems are again old practices in which the great majority of the disabled people is currently living. Someone who has been for the most of the life a passive receiver of help needs some time and a great deal of effort to break away from this ready-made role, to decide and make step forward into the area of unknown and uncertain. The obstacles posed on this path are presented by the people who are close to this individual (parents, relatives), who often oppose or even prevent an act of emancipation. Objections are often completely banal, namely that he or she is not capable, does not possess enough strength or does not know how to do it. It is hard to believe how many experts must be fought off by a person who has decided to set foot on the path of independent living and self-determination. We are saddened by the fact that of all people, the persons who were educated to advise in various fields of social assistance pose the greatest obstacle on this path, even though they should, bound by duty, above all cater for user’s requirements and wishes.

This article was presented on the first congress of social work, Portorož, 17 – 19 October 2002.

Klaudija Poropat, Emil Bohinc

Personal assistance in the light of employment

Personal assistance requires an active individual who is capable of decision-making and accepting the consequences of his or her decisions. Enactment of this basic right (Act on equal opportunities for disabled persons) will in addition to changing the position of a disabled individual, also fundamentally change the area of employment of personal assistants:

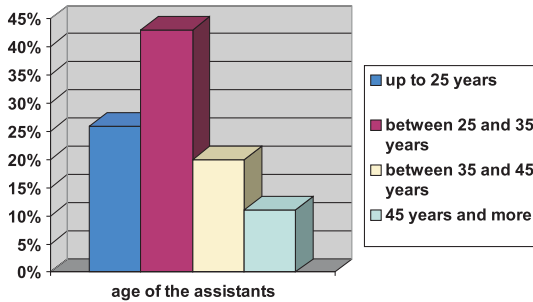
1. At the moment, personal assistance is tied to financing through our project, however when an individual will be able to take care of the financing aspect by him or herself, there will be more room for an independent decision-making. Either an individual will leave the decisions concerning employment to certain organizations or he or she will accept the role of a formal employer and will not make use of such organizations. Change of form of financing will without doubt have an impact on further development of this activity, for in spite our best endeavours, financing through a project is still limiting and uncertain – one never knows what a certain government decision shall bring and whether one shall succeed in securing enough of the resources for an unhindered execution of the programme. Financing through a project is by no means the best solution, however in our current social care scheme it is the only one possible.
2. Currently, the “personal assistant” occupation profile is still unfinished, which gives us considerable freedom with respect to searching for, choosing and finally “moulding” the assistant so that he or she fits the needs of an individual user. For more information on this question and on what profesionalisation of this occupation shall bring, please see an article by Elena Pečarič.

In our society, we have considerable experience with employing personal assis-

tants. In 1998, when we started an extended version of the “Independent Living” programme, there were 15 users involved and we were employing only 18 assistants. Currently, there are 68 users involved and we are employing 67 assistants. In 1998, the programme was being executed in four different municipalities, now we are covering 10 of them. Evidently, personal assistance is also important in the light of employment. In times when unemployment is considerable, we have created a new profession and in doing so, filled a niche in the field of social care programmes and furthermore in a way linked the need of the disabled for new ways of living (outside institutions) with a new employment option. Moreover, this form of employment is uncommon, because it is subsidized. Therefore, it includes groups of people, who are, by certain indicators, difficult to employ. At first, the assistants were employed only through the Public Works programme and were supplemented with volunteers. Later they were additionally included through the A Thousand New Chances programme and currently most of them are employed within the sphere of the Disabled for the Disabled – Personal Assistance programme. Yet we still make use of the Public Works programme. This enables us to train the assistants and gives us a chance to get to know them, before we employ them for a longer period. Quantity of the volunteers has meanwhile declined.

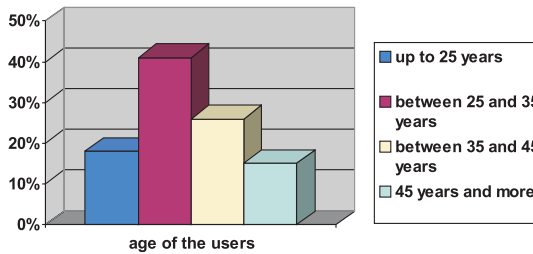
Main characteristic of our programme is individual treatment - not only of the users of the programme, but also of the personal assistants. We cannot overlook the fact that our assistants are employed through subsidized employment programmes, which means that for various reasons they have found themselves in the category of people with low employment prospects. In these programmes, we cannot employ the people who are registered at the Employment Office without making careful selection. Such a person must conform to various criteria, which are designed by the Employment Office in accordance to the governmental policy of unemployment reduction (e.g. duration of subscription at the Employment Office, persons with no prior work experience, persons without formal education, single parents, elderly persons...) . These persons, who are not desirable in other sectors, have shown to be indispensable in the role of personal assistants. Since their entrance into our project, quite a few of them have taken a path completely different from their previous work experience or their formal education.

So, what are the key characteristics and skills we are looking for when we are interviewing candidates for personal assistants? If we look at the graphs of assistants listed below (the data was collected in October 2002 when 50 users were included into the programme and 46 assistants were employed), we can clearly see that the age of most of the assistants is between 25 and 35 years, however other age groups are represented as well. In comparison to the age of the users, one can draw similar conclusions. The numbers confirm our experiences – most of the users want and choose an assistant of their age group, in other words an assistant who is their peer.



age of the assistants

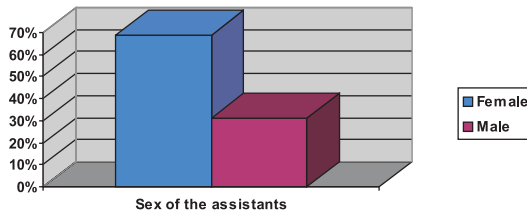
up to 25 years	- 26 %
between 25 and 35 years	- 43 %
between 35 and 45 years	- 20 %
45 years and more	- 11 %



age of the users

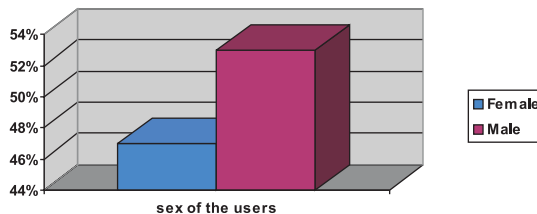
up to 25 years	- 18 %
between 25 and 35 years	- 41 %
between 35 and 45 years	- 26 %
45 years and more	- 15 %

With respect to sex, we can see that 69% of our assistants are female and 31% male. Among the users on the other hand, males are in slight majority (53 %M in 47 %F). Most of the female users have female assistants, however only a smaller part of our male users employs male assistants – majority of them employs females.



sex of the assistants

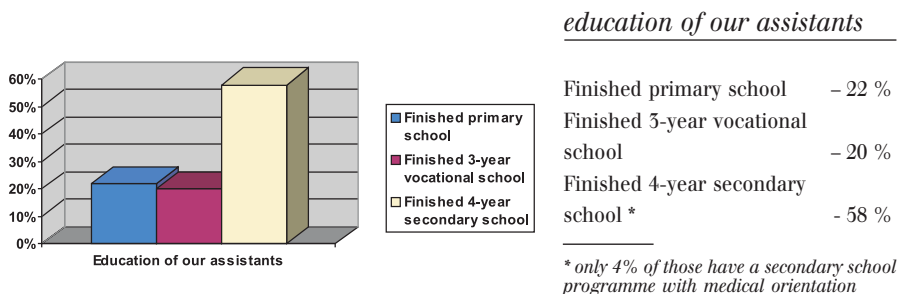
F	- 69 %
M	- 31 %



sex of the users

F	- 47 %
M	- 53 %

Education structure of our assistants shows that most our assistants have finished secondary school and almost a quarter of them have only finished primary school. Contrary to popular belief, only 4% of the persons have received “medical education”.



All of the statements asserted above are confirmed by our practice. In individual service of which “Independent Living – Personal Assistance” is an example, we cannot define a clear profile of persons, who might be suitable for this occupation in advance. Standardizing can lead to exclusion of the assistants who – based on our experience – are doing an excellent work. As much as one cannot say that only the young between 25 and 35 years of age can live independently, one must also not claim that this age group manages its assistants in the best way. The criteria of education and sex have also proven to be irrelevant. Not only people who have finished secondary school are accepted into our project. Moreover, uneducated persons who have finished only primary school are performing their work at least as well as their more educated colleagues. What is more, contrary to common belief and care practices, male assistants are doing a splendid job. The same pattern appears with respect to work experience – most of our assistants had no experience with dealing with the disabled persons before entering our project. **Still, there is a single characteristic common to all assistants – they are not prejudiced against the disabled persons and have not established a relationship of a caretaker with them. If that were the case, an individual would be unable to build on establishing his or her independence.**

An approach, which we favour in our programme, also covers employment of the assistants. We therefore favour individualisation of the services. Although this approach requires a lot of work, cooperation, consultation.... it has proven to be by far more satisfying in comparison to the institutionalized and standardized approaches and has been decided to be the only acceptable approach since the very beginning.

When we get to know the user and his or her wishes and needs, we can start looking for a suitable candidate in cooperation with the Employment Office, who suits at least the basic needs of the user. Nevertheless, we only find the

candidates. This is just a beginning. Both, the user and the person who decided for this occupation bear responsibility of choosing and training the assistant. In any case, we, the designers of the programme, may only advise and take care of the formalities regarding employment, whereas the user and his/her assistant themselves are obliged to give assurance of mutual respect and of performing their work at a satisfactory level.

At the end, we would like to say something about the future of personal assistance. Surely, it shall change. However, it depends, which direction this change shall take. Direct financing shall bring a possibility of choosing among the potential candidates, however we will have to fight against the limitations that are unacceptable for us and are materializing in continuing pressure to standardize our approach by the rules of institutions. Which of our assistants could be excluded from our project and based on this criterion, whoever might get accepted... all these questions shall be the topic of future debates, which shall take place before the Act on equal opportunities for disabled persons takes its final form.

This article was presented at the First Congress of Social Work in Portorož, between 17th and 19th October 2002 and was revised for this bulletin in January 2004.

Occupation profile: Personal Assistant

Profile of the occupation was designed in 2002, when Elena Pečarič was invited into a group of experts who were supposed to design a “personal assistant” occupation profile. The subscriber of this project was Ministry of Labour, Family and Social Affairs and the contractor was Centre of the Republic of Slovenia for Vocational Education and Training. The profile was supposed to serve together with the Act on equal opportunities for disabled persons. In the very beginning, when the first and only meeting took place, it was clear that we do not agree in what the theme of our talks should be. Several months passing resulted in a proposal, which was completely unacceptable to us, as the personal assistant was reduced to a nurse or a social caretaker. Therefore, we have decided to make a stand against such an interpretation and have designed our own proposal.

FIELD OF WORK	TASKS (a few concrete examples) primerov)
Care and assistance in all the activities the user wishes or needs to take part in.	<ul style="list-style-type: none"> - personal care, change of clothes, toilet. - help with taking a bath and washing - help with feeding and drinking - for the blind persons the assistant reads daily newspapers, mail etc. - help to get in the wheelchair (by use of elevators or lifts if necessary)
Escort	<ul style="list-style-type: none"> - assistance with moving around; driving the wheelchair, help with installing and control of orthopaedic and technical appliances, leading

	<p>and orientation of a blind person or assistance to a deaf person</p> <ul style="list-style-type: none"> - assistance with taking care of errands, shopping, attending free time activities, various performances, escort when travelling ...
Assistance with menial tasks	<ul style="list-style-type: none"> - to cook according to the user's instruction - to wash and iron laundry - to tidy up in the presence and upon the instruction of the user - to take care for the user's/parent's child in his/her presence and according to his/her instructions (completes half of the menial tasks, the other half is done by the user)
Help on the workplace, and in the process of education	<ul style="list-style-type: none"> - to help with the activities the user needs to perform on his workplace; to install various accessories the user needs to perform these activities - to read, type and arrange various documentation and literature for the blind persons
Maintaining quality	<ul style="list-style-type: none"> - to protect user's personal data - to respect user's intimacy - to respect ethical principles, principles of independent living, that is, user's decisions and his/her sovereignty - to respect other accepted rules, agreements and duties stated in the contract
Communication	<ul style="list-style-type: none"> - with the user - with other persons only upon his/her request and with his/her authorization - with others when there are sensorial or other obstacles concerning communication, for which the user needs some help to overcome, communication with user's parents or guardians only when the person is a minor or is mentally challenged to a greater extent - with the person responsible, who implements supervision or solves conflicts settles the disputes - with a person responsible inside a service, society, organization or a firm etc. - z odgovornim na servisu, društvu, organizaciji ali podjetju itd.

QUALITIES OF A PERSONAL ASSISTANT

They are set by the user based on needs and wishes:

- responsibility, punctuality, assiduity
- understanding with user
- correctness, reliability

UNDESIRED QUALITIES

- patronage and guardianship
- pity
- treatment of the user as a patient

Key differences in values and principles between the traditional designers of social care policies and the “user” organizations

Values of the traditional policies	Equal rights values
care	Participation, taking part in decision making
medicalization	Activeness in designing strategies policies
segregation	participation
profession	empowerment
»family problem«	self-determination
normalization	civil and human rights
charity	equality, equal rights
adjustment	ability to choose
correction	independence
compensation	responsibility
special needs	autonomy
social integration	solidarity

Differences in the policy of treatment with regards to the models of values: treatment and the solution of the problem depends on what we will see as a “problem” and where it will be placed (all the methods and ways of addressing the problem depend on that)

Placement of the problem	Perception of the problem	Most probable answer/ways of solving
In the individual	accident injury dissimilarity (in comparison to others) loss disability / limitedness support / help	charity healing / rehabilitation segregation acclimatization »supplemental« therapy care
In the societal environment	prejudices social circumstances architectural obstacles discrimination oppression	education, making the public aware, real-life examples, direct financing civil rights, anti-discriminatory legislation political struggle

Differences between the profile of a “social assistant” and the profile of a “personal assistant”:

Domestic assistance is not an autonomous service, as it does not suffice the users who need a lot of help or 24-hour care and it can therefore only be supplemental or even better, it can relieve some of the burden off the family’s shoulders. Such form of help may only be suitable for the users who need it periodically or have their own network of people who can help them. The service is bound by the Social Assistance and Social Services Act and by the book of regulations on standards and by the catalogue of services regarding social welfare. Since it is not a full-time assistance, it only incorporates necessities, such as feeding, bathing, changing clothes. The relations between the social assistant and the user are therefore completely different in comparison to the relations between the user and his personal assistant. Personal assistance incorporates all the tasks that the user needs to have implemented and as a rule lasts eight or more hours a day. The social assistant is not independent in making decisions, because his/her superior gives him/her exact instructions as to what the users need. They receive these instructions from chiefs of the regional unit based on

the contract or an agreement previously signed. He or she does the work only because it has been determined that the user will benefit from such a service and that he or she needs it (in most cases the user does have much say when the contract is made, especially when elder persons are in question)

Personal assistant is a person, who is selected by the user based on his/her own criteria, is properly educated by the user and is taught how to assist. A personal assistant sticks to the user's instructions and is usually not responsible for the user's actions. The work of the personal assistant is of course limited in the fact that he/she is not a housework assistant, however he/she should implement all other tasks the users needs or wants them to be done. The assistant's working hours are also set by the user and all the agreements (within the boundaries of the legislation and rules) concern only the parties affected.

Translations: Gregor Fajdiga, Vita Nastran, Mirica Ačko, Katarina Gorenc, Elena Pečarič

Proof reading: Mojca Lukner, Ivo Poderžaj

Cover illustration: D.Lumpert & C. Horjak

Design: Epsit d.o.o.

Print: Martin Ribič s.p.

*Publication has been financially supported by: Office of RS for
information and Embassy of the USA in Slovenia.*



*YHD – Association for the theory
and culture of handicap
Neubergerjeva 7, Ljubljana
Office: Kotnikova 5, Ljubljana, Slovenija
Tel.: ++ 386 1 430 17 60, 01 230 16 57
Tel. & Fax: ++ 386 1 431 20 54
E-mail: yhd@mail.ljudmila.org
Web page: www.ljudmila.org/yhd*

